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Coping with HIV/AIDS Stigma in Five African Countries

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Abstract

People living with HIV (PLWH) and their families are subjected to prejudice, discrimination and hostility related to the stigmatization of AIDS. This paper examines how PLWH cope with HIV-related stigma in the five southern African countries of Lesotho, Malawi, South Africa, Swaziland, and Tanzania. A descriptive, qualitative research design was used to explore the experience of HIV-related stigma of PLWH and nurses in 2004. Forty-three focus groups were conducted with 251 participants (114 nurses, 111 PLWHs and 26 volunteers). In describing incidents of stigma, respondents reported strategies used or observed to cope with those incidents of stigma. Nurse reports of coping strategies that they used as well as coping strategies they observed as used by HIV-infected patients were coded. Coping strategies used by PLWH in dealing with HIV-related stigma were coded. Seventeen different self-care strategies were identified: restructuring, seeing oneself as OK, letting go, turning to God, hoping, changing behavior, keeping oneself active, using humor, joining a support or social group, disclosing one's HIV status, speaking to others with same problem, getting counseling, helping others to cope with the illness, educating others, learning from others, acquiring knowledge and understanding about the disease, and getting help from others. Coping appears to be self-taught and only modestly helpful in managing perceived stigma.

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Keywords

HIV; AIDS; nursing; stigma; Africa; coping; quality of life

People living with HIV (PLWH) and their families are subjected to prejudice, discrimination, abuse, and hostility related to stigma associated with HIV (Holzemer & Uys, 2004). This disease continues to evoke wide-spread public fear of the disease and condemnation of those afflicted by it. Goffman (1963) wrote that stigma refers to undesirable attributes that are congruent with our stereotype of what a given type of an individual should be. Stigma has its origins deep within the social structure of society as a whole and in the norms and values that govern every day life (Nyblade et al., 2003).

Hoffman (1996) reported on the relationships between health status, stigma, and ways of coping and demonstrated that HIV infection was inherently stressful and had a major influence on quality of life. Research has demonstrated that HIV-related stigma can have a variety of negative effects on health behavior, such as seeking HIV testing, willingness to disclose HIV status, accessing health care, and on quality of health care provided or received (Brown, Trujillo, & Macintyre, 2001). Lee, Kochman, and Sikkema (2002) found a significant relationship in PLWH between greater severity of symptoms and higher level of internal HIV stigma. In Botswana and Zambia, researchers found that stigma against HIV-infected people and fear of being mistreated prevented people from participating in voluntary counseling and testing (VCT), including programs aimed at preventing mother-to-child transmission (Nyblade et al., 2003).

The success with which PLWH cope with the continuous stress attached to HIV has a direct impact on quality of life. Alonzo and Reynolds (1995) described the life of an infected individual as a constant struggle to cope or manage stigma. The way in which individuals discover and disclose their HIV status to others as well as how they cope with their infection is influenced by cultural and community beliefs and values regarding causes of illness, learned patterns of response to illness, social and economic context, and social norms (Brown et al., 2001). Coetzee and Spangenberg (2003) documented that problem-focused, active coping styles were superior to emotion-focused, passive coping styles, such as avoidance, in reducing psychological distress.

Siegel, Lune, & Meyer (1998) described strategies of coping with stigma among gay/bisexual men. They described a variety of strategies that could be arranged in a continuum from reactive to proactive based on the extent to which the person implicitly accepted or challenged the social norms underlying stigmatization of HIV. Reactive strategies were used by respondents to avoid being discredited through hiding HIV status and controlling information about HIV within one's close social network. Proactive strategies were used to construct and promote alternative views of HIV that undermine societal stigma. The most proactive responses addressed the meanings, values, beliefs, practices, and power imbalances behind the stigma rather than situations in which stigma might be experienced.

Moneyham and colleagues (1998) reported research on coping in chronic conditions and indicated that the use of avoidance coping strategies was consistently associated with increased psychological distress, including anxiety, depression, and poor adjustment. However, these authors also reported that active and avoidance coping in women with HIV was significantly related to physical symptoms, with active coping positively related to physical symptoms and avoidance negatively related to physical symptoms. They hypothesized that this might be the result of avoidance being used as a coping strategy in the early stages of the disease when

symptoms were fewer, while onset of disease-related symptoms evoked use of active coping strategies.

This paper explores coping strategies employed by people experiencing stigma because they are living with HIV in the five southern African countries of Lesotho, Malawi, South Africa, Swaziland, and Tanzania.

Methodology

Research Design

A descriptive, qualitative research design was used to explore the experience of HIV-related stigma of PLWH, nurses working with HIV-infected clients, and volunteers working with HIV-infected persons. During focus group discussions, participants were asked to relate incidences that they observed as well as those that they experienced in the community and in families related to stigma. Participants were also asked to define their own understandings of what stigma and discrimination meant (Uys et al., 2005). This article reports on an unintended outcome of these focus groups, which was the descriptions participants gave of mechanisms PLWH used for coping with the stigma associated with the disease.

Settings

The study was conducted in 2004 in the five African countries of Lesotho, Malawi, South Africa, Swaziland, and Tanzania. In Lesotho and Swaziland focus groups involved people from all administrative regions of the country. In South Africa, Malawi, and Tanzania only one geographical area with a more-or-less homogeneous population was included. In South Africa the setting was the Potchefstroom urban area and the Kayakulu rural area, both in the North-West Province. In Malawi, Lilongwe was used, and in Tanzania the urban setting was Dar-es-Salaam, and the rural setting was Mbeya.

Sample

Forty-three focus groups that included a total of 251 participants (see Table 1) were conducted. The participants were PLWH (44%, $n = 111$), nurses and nurse managers (45%, $n = 114$), and volunteers/youth groups (10%, $n = 26$). The overall mean age of the participants was 39.9 years. Women constituted 53.1% of PLWH, 95.1% of the nurses, and 58% of the volunteers. Of the focus groups, 55.8% were conducted in urban settings and 44.2% in rural settings. The sample was approximately equally divided amongst the five countries.

Data Collection

All participants completed a brief demographic questionnaire. A focus group discussion guide outlined two questions: "How do people you know refer to people living with HIV?" and "Can you share an example of stigma or discrimination directed toward a person living with HIV, their family members, or nurses who care for them?" Probes were used to elicit further details of the incidents described.

Focus group discussions were conducted in the local languages of the five countries, since all the respondents, including the nurses, were more comfortable expressing themselves in the local language. In South Africa participants used Afrikaans, English, Tswana, Sotho, and Zulu. The co-researcher simultaneously communicated with participants across these languages. The following languages were used in the other countries: in Malawi, English and Chichewa; in Lesotho, Sesotho; in Swaziland, Swazi; and in Tanzania, Kiswahili. The sessions were audio recorded, transcribed verbatim, and translated into English. In South Africa, the discussions were translated into English during the transcribing process. Nvivo™ software was used to code demographic attributes (country, type of participant, gender) and themes.

Protection of Human Subjects

The research protocol was approved by all seven of the Universities involved (see author list), providing protection of human subjects. Permission to conduct the study was also obtained from the appropriate local and central government authorities. Participants were provided with information about the background of the study and informed that participation was voluntary and that they could withdraw from participating at any time. Participants were also assured of confidentiality of information obtained. Following this explanation, participants each signed a written consent form.

Data Analysis

A coding system of three major types of stigma (received stigma, internal stigma, and associated stigma) was used as a starting point for the data coding (Insideout Research Report, 2003). Five transcripts, one from each country, were carefully studied by the research team to determine sub-themes under each type of stigma, using the open coding technique (Corbin & Strauss, 1990). Eight sub-themes of received stigma were identified (neglecting, negating, avoiding, rejecting, labeling, gossiping, pestering, and abusing), four sub-themes for internal stigma (negative perceptions of self, social withdrawal, self-exclusion, and fear of disclosure), and two sub-themes for associated stigma (nurses and other health workers). Four additional themes, not related to types of stigma, were identified (results of stigma, settings of stigma incidents, sources of stigma, and disclosure).

In describing incidents of stigma, respondents reported strategies used to cope with those incidents of stigma. In some cases, respondents reported the coping strategies spontaneously, and in other cases the interviewer probed and elicited the strategies. Nurses reported on coping strategies that they used as well as coping strategies used by HIV-infected patients. For this article, transcripts were recoded to capture incidents of coping with HIV-related stigma.

Results

During the 43 focus groups conducted with 251 participants (114 nurses, 111 PLWHs, and 26 volunteers), a total of 137 coping strategies were described.

Coping strategies used to deal with HIV-related stigma were coded. Seventeen strategies were identified; 6 were labeled emotional and 11 were labeled problem-focused (See Table 2). Emotional coping strategies (44.9%) were activities the person could do alone, involving emotional self-management. Problem-solving coping strategies (55.1%) involved addressing the problem more directly and engaging with others.

Emotional Coping Strategies

Rationalization—This category was used for cognitive processes that seemed to make the diagnosis and the stigma less painful or to question the basis of stigmatizing behavior. In this category, respondents indicated that they focused on positive thinking and having alternative explanations for their illnesses as reflected by the following statements:

I told myself that all of us are dying. There is no one who will remain in the world.
(Urban, HIV-infected female)

I expect two things - people will talk about me or they will not. If they do not talk about me, I am not human. "A human being cannot talk to a horse," people talk about people. (Urban, HIV-infected female)

So I just told myself that this illness is just like TB, ulcer, and so on. It didn't really hurt me that much. (Urban, HIV-infected male)

Seeing self as being OK—This category included thoughts about seeing one's self as normal or as OK and courageous in the face of the illness or stigma. Some participants expressed this feeling by not restricting themselves or withdrawing from social contact.

I told my sister that, if it was that “thing” (AIDS) for as long as I lived, I was going to beat it. (Urban, HIV-infected male)

When I am attending a social gathering, I do things in a normal way. I don't restrict myself on what to touch and what not to touch. (Urban, HIV-infected female)

Letting it be—This category referred to avoidance of confrontation and passively accepting or ignoring stigmatizing behavior. Sometimes respondents resorted to ignoring challenges of stigma directed to them.

I just become patient with them, and I tried to avoid confrontations with them. There was nothing else I could do. (Urban, HIV-infected male)

My children made me sit down. They begun to tell me everything that was said there about me, but I did not say anything. I just said, “Leave it because this disease is an epidemic, it has spread throughout the world.” We also do not know where he (spreading the gossip) has heard this from because if he is young he cannot know about these things, but he must have been told by somebody who is older (pause), and my children asked me what we were going to do with them? I said, “No, you just leave it (pause), when you leave it like that they will feel guilty.” Since then they never spoke those words again because my children did not approach them to ask or talk it over with them. (Rural, HIV-infected male)

Turning to God—This coping strategy focused on spirituality and included activities such as praying, joining religious groups, depending on and building hope in God in response to the illness. The majority of participants reported that their faith in God was central to what kept them going.

The most important thing is I like to pray so much, associating with people who pray, chatting with friends who are jovial, and, when somebody says something bad about me, I do not care, I just say, “Lord forgive him/her because he/she does not know what he/she is doing,” and I encourage others who are in the same predicament. I tell them to pray, and they should not forsake God. (Urban, HIV-infected female)

I prayed to God. I told God that those who are boastful without you they are useless. I am sleeping here now, and I know that you will take care of me. I used to stay like that, sleeping and waking up, but nothing bad happened. (Urban HIV-infected female)

Hoping—References to hope were not linked to any specific source of hope (such as religion). It was the hope that all would change without any intervention.

After knowing that I was infected with HIV, I was shocked, but I knew I would live with hope. (Urban, HIV-infected male)

You may be infected, but you can live with hope. (Urban, HIV-infected male)

Humor—Using joking about the illness or stigma tended to lessen the fear and seriousness associated with HIV.

We (nurses) gave him (the HIV-infected male) his own utensils (said with laughter). He was a graduate, so he realized that was a joke, and he used to say in a joking way that he would not touch our things. (Nurse, Urban)

Among people who make jokes, you forget. You don't think about death, you enjoy life. (Urban, HIV-infected male)

Problem-focused Coping Strategies

Joining a Group—Joining a support group or associating strongly with others who had HIV were coded into this category. The groups were not only formal support groups but also informal groups.

This is why orphans with child-headed families have developed some defense against the communities they live in. They firmly stick together, they protect each other and have accepted the stigma and isolation. (Rural clinical nurse)

But after joining the support groups for people living with HIV, I started getting the challenges, I became courageous. I never cared about those who stigmatized me anymore. I started attending funerals, just like other people. So, really that happens to most of us. (Urban, HIV-infected female)

But I thank God that when I joined SWAA-T I found many people like me. I also joined another organization, PASADA. I am still surviving until this moment. (Urban, HIV-infected female)

Disclosing—Some participants reported being open and truthful about being infected with HIV. Some served as spokespersons for people with the illness. Some disclosed their HIV status to reduce gossip and rumors, while others disclosed their HIV status seeking to solicit support from loved ones and community members.

I went to the chief and asked him to organize a gathering so that I could disclose my status to the whole village. He did. I didn't want anybody to gossip about my status. My community accepted me, and one woman volunteered to give me support whenever I need it. (Urban, HIV-infected female).

That is why I voluntarily offered to talk on TV Malawi. I wanted people to understand because I did not get the virus through prostitution. (Urban, HIV-infected female volunteer).

So it is better if you disclose in order to help those who don't know about it. The best thing is just to inform friends and family so that when you go out you know that you have got support around you. (Urban, HIV-infected male)

Going for counseling—This category referred to reaching out to receive formal and informal counseling from health workers, counselors, or from peer counseling by other HIV-infected persons. HIV-infected participants reported that counseling helped them feel better and made them understand their illness better.

They told me, "Don't worry; you should be like this and don't be like that. Do this, don't do that," and so on. They said there are many people who face the same problem. Actually, that eased my tension, and I felt better. I knew from that time that there were other people suffering the same problem but live with hope. (Urban, HIV-infected youth)

Over a period of time, counseling gradually transformed me, and I became accustomed to my condition. The fear that once shadowed my life vanished away. (Urban, HIV-infected female)

I did not worry about the results. I was just thinking of the children. What made me not to get worried was the counseling that I was given. (Rural, HIV-infected female)

Talking and chatting to others—This category referred to informal socializing and talking, sometimes about the illness and its results, but sometimes just about social topics.

I don't like to be alone. I like to be among people. I like to chat with people. It makes me forget that I am sick with that disease. And it feels good. (Urban, HIV-infected male)

On weekends I go to my aunt in Klerksdorp, or phone my sister in Stilfontein. I've told her about my illness, and we sit and talk. At times I tell my church leader. He tries comforting me with the Bible. (Urban, HIV-infected female)

Helping others—Some participants provided descriptions of coping by becoming involved in helping others, mainly with HIV-related problems.

As the sister (nurse) goes out for home-based care I go along with them to visit the patients. Those who cannot come to the clinic, but still not bedridden, I encourage them to stand up and go the clinic. There is one who drinks alcohol, the nursing sister requested me to visit him and talk to him so that he can stop drinking and then attend treatment. (Rural, HIV-infected female)

You may find a person being happy during the day, at night he/she is at your door knocking, asking for your help. Actually, I keep alert, and I normally render the service. Many of them I managed to convince them to undergo for the test, some were found to be positive and others did not have problems. (Urban, HIV-infected youth)

Educating others—This category referred to the active teaching of others as a coping behavior and also as a means of helping others to cope.

Within my area, I do educate people, and some of the people I convinced and helped them to go to the clinic. (Urban, HIV-infected youth)

The actions I took are, just being close to them and educate them about how the disease is transmitted, how to deal with the situation after they contracted the disease. Further, they should not think that when they are infected now they are dying people - that is not true. You may be infected, but you can live with hope, and if you follow the advice, such as to minimize the frequency of sexual act and pray to your Almighty God. (Urban, HIV-infected male)

Changing lifestyle—These descriptions referred to people coping by changing their behaviors and lifestyles. Some cited how they were determined to change their lifestyles, and such positive changes then became the focus of their lives, rather than the negative diagnosis.

I had to change my lifestyle and told myself that living with HIV means beginning of a new life. (Rural, HIV-infected male)

When I saw these developments I told myself that I could not be infected. I have since decided to lead a healthy life. I watch my diet and will never sleep with my husband again. (Urban, HIV-infected female)

Keeping busy—Keeping busy or concentrating on what needed to be done rather than on feelings was reported as a coping mechanism.

If you feel there's something that you want to do, do it yourself. If you want to do something, do it, do anything you want to. Sometimes when I am not very sick I often take a spade and do a little bit of gardening so that I do not stress a lot. I do not want to be forever in bed. If you do not strengthen yourself you will never wake up. (Rural, HIV-infected female)

I have learned tailoring, and I am now engaged in sewing and weaving tablecloths.
(Urban, HIV-infected female)

Acquiring more knowledge—People coped by getting involved in information seeking in order to understand the disease.

So sometimes I had to ask for permission to attend different HIV seminars to acquire more knowledge. (Urban, HIV-infected male)

I did more about looking for the AIDS education. That is, reading newspapers, making follow-up in radios while I'm at home. (Urban, HIV-infected male)

Learning from others—This category described how people learned to cope by following positive role models, or learning from others who had HIV. The statement below shows that success stories encourage one to live with HIV:

You will find someone telling you that, "I have lived with HIV for 14 years now"; another also says, "I have lived with the problem for six years now"; and so on, and therefore, I knew since that day that the problem is HIV, not AIDS. OK, thank God for helping me to know that, and now I have accepted the situation, so, now I enjoy the life. (Urban, HIV infected youth).

Discussion

While a number of coping strategies were reported by these participants, rationalizing was reported with the highest frequency, indicating the internal conflict persons living with HIV experience with the diagnosis and acceptance of the infection. Coping by rationalizing is consistent with the literature. For instance, Faber, Mirsalimi, Williams, and McDaniel (2003) reported that finding positive meaning in illness had beneficial effects on psychological adjustment to the disease and suggested it may even be associated with protective health effects. Participants in the Faber et al.(2003) study who reported more positive meaning to their illness reported higher levels of psychological wellness.

Some data suggest that HIV-infected persons may seek to restructure their situations in ways that might be negative or destructive for themselves or for others. For example, Nyblade et al. (2003) reported on a study in Ethiopia, Tanzania, and Zambia that explored coping strategies used by HIV-infected persons. They found that PLWHs looked for alternative explanations for contracting the virus besides sexual transmission, by either believing in witchcraft or in HIV being given by god. Witchcraft, when believed as the source of infection, provided a sense of protection against stigma and was perceived as out of the control of the individual.

Disclosure was used carefully as a coping strategy, depending on whether it was judged to make things better or worse. Disclosure as a coping strategy was used mostly in situations when the PLWH thought disclosure might lead to support from spouses and family members. Insideout Research Report (2003) found that disclosure was the most challenging action to take, as many feared being judged, being rejected by a spouse and family members, and being rejected by the community. However, not all respondents in their study faced negative consequences when they disclosed their HIV status. We found that participants reported that they felt relieved after disclosing, especially to a spouse or family member, as if something had been lifted from their shoulders. Brown et al. (2001) reported that non-disclosure, denial, and hiding could also be a way of coping, especially if it protected one from stigma.

Involvement in a support group or identifying one's self with individuals who suffer the same condition was an acknowledged way of coping with stigma (Nyblade et al., 2003). Majumdar (2004) reported that participating in social networks reduced physical and social isolation due

to HIV status. She reported an example of some women in India who were forced to reside on the outskirts of their villages because of their HIV status. However, their social networks provided a social support system and a sense of worth in their lives. Contact with HIV-infected or -affected groups through face-to-face conversations or hearing testimonials has been used in many studies as a means to reduce stigma (International Council of Nurses, 2003). Aggleton and Parker (2002) reported that participating in support groups may or may not demystify and dispel misinformation and generate empathy, which, in turn, reduces stigma. Within a community context, HIV-related stigma and individuals affected by stigma, can lead to the development of support structures and mechanisms for other PLWHs, thus coping with HIV-related stigma can be used as a positive tool for societal change around this phenomenon (Horizons Program, 2002).

Coping by seeing one's self as OK is a strategy that reflects a strong will to survive in the face of illness. This was manifested through being socially active and participating in community and social gatherings. Talking to others builds social networks through formal or informal networks, and these networks provide platforms where all can tell their stories, share their pain, chat, and develop friendships. Nyblade et al. (2003) reported on a woman who said that when she met with and saw each one of the support group members crying, she knew that they shared the same problem. They talked about their illnesses and began to visit each other.

Coping by letting it be or avoiding confrontation is a passive way of protecting one's self. Some researchers (Horizons Program, 2002) believe that being proactive in disclosure may expose the stigmatized person to more stigma and discrimination, including violence, and they support the coping strategy of being more passive. Others argue that avoidant behavior can lead to activities or mental states such as social withdrawal, increased alcohol consumption, or risk-taking behaviors, that keep them from directly addressing the stressful event.

Several studies (Insideout Report Report, 2003; Majumdar, 2004; Nyblade et al., 2003) reported that becoming more religious and getting comfort through immersing one's self in religion was common as a coping strategy. Religion plays a vital role in the care of HIV-infected persons and their families. Religious participation provides spiritual and emotional support, offering religious leaders an opportunity to incorporate ways to reduce stigma in community services. Spirituality emerged as coping strategy in this study and was manifested through prayer, meditation, and hope in God. Religion as a self-care strategy for HIV has also been reported as a strategy to relieve HIV-related symptoms (Chou, Holzemer, Portillo, & Slaughter 2004).

Collymore (2002) and Horizons Program (2002) reported that HIV-infected persons who got counseling, acquired more knowledge, and learned from others, did better than those who adopted passive strategies. The Insideout Research Report (2003) stated that HIV-infected participants who experienced supportive environments, such as support of families, religious faith groups, non-governmental organizations such as an AIDS support group, AIDS training, and counseling centers, had success in overcoming internal stigma. The majority emphasized the importance and the value of counseling, information, and support groups in the journey to overcoming the emotional upheavals of discovering their HIV status. Counseling and health information have been reported to empower HIV-infected persons to change risk behaviors and to adopt healthier lifestyles.

Nurses, like other health workers, have been recipients of stigma because they care for PLWHs, and they may also be the source of stigma (Holzemer & Uys, 2004) Nurses require knowledge, support, and understanding of the illness in order to cope with stigma associated with the care they provide. Nurses can access continuing education programs to gain additional knowledge and skills that will enhance their abilities to deliver quality patient care and to provide support

for people living with and affected by HIV. Nurses can work to empower HIV-infected persons and their families by providing appropriate knowledge, counseling before and after testing to prepare them to cope with the diagnosis, and strategies to assist with disclosure.

Conclusion

Within the African context, in which this study was conducted, coping appears to be self-taught and only modestly helpful in managing perceived stigma. This finding differs from international trends, such as the work of Collymore (2002) and Horizons Program (2002), which report that adequate counseling, knowledge, and information learned by PLWHs can be used as coping strategies. The findings of this study also highlighted that coping within the context of HIV can be used as a positive mechanism for stigma reduction and, as such, nurses and other health care workers who care for PLWHs and their families need to develop a greater understanding of the challenges faced when coping with HIV disease. Further research is recommended in order to develop a greater understanding of the effectiveness of these self-reported coping strategies for dealing with stigma.

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Table 1

Participants by Groups, Gender, and Age Combined Over Country

Groups	# Groups	Men	Women	Total Sample	Mean Age	Urban Group	Rural Group
PLWH	19	52	59	111	36.8	9	10
Nurses	20	5	109	114	42.7	12	8
Volunteers	4	11	15	26	34.3	3	1
Totals	43	68	173	251	39.9	24	19

Table 2
Emotional and Problem-focused Coping Strategies ($n = 127$ separate strategies)

Emotional Coping Strategies	Frequency and (%)	Problem-focused Coping Strategies	Frequency and (%)
Rationalization	22 (35.1)	Joining a group	15 (21.4)
Seeing self as OK	10 (17.5)	Disclosing	15 (21.4)
Letting it pass	8 (14.0)	Speaking to others	9 (12.9)
Turning to God	8 (14.0)	Getting counseling	6 (8.6)
Hoping	7 (7.0)	Helping others	6 (8.6)
Humor	2 (3.5)	Educating others	5 (7.1)
		Changing behavior	4 (5.7)
		Keeping active	4 (5.7)
		Learning from others	3 (4.3)
		Acquiring knowledge	2 (2.9)
		Getting help	1 (1.4)
Total	57 (44.9)	Total	70 (55.1)